

III

SHARED ACTION-TAKING AND TEAM BUILDING

LINKING AND RECONNECTING TO NATURAL AND COMMUNITY SUPPORTS.

Creating contexts for change is a theme on using connectedness and coming together in the service of health and learning . We use these methods as interpersonal bridges from which we open reciprocal ways to exchange and mutually support each other. We see in each other's eyes something bigger is at stake than our individual selves. Through our communal evolutionary need we can satisfy in part life's meaning, direction and purpose. One such purpose is our needing one another. We need connections that matter and that are heartfelt. Such is the dedication to this need to connect and reconnect to husbands, wives, brothers and sisters, partners, friends, neighborhoods and communities bringing together our traditions, stories, pasts and future aspirations, hopes and dreams. (Hallowell, 1999)

We propose several practices in seeking ways to take action together including among them family unity, child attachment, finding a friend and building allies which are summarized below. We suggest looking at our Community Self Help section of the web site under About Us on the menu as a help in tandem with Team Building while offering multisteps in concrete ways on how to start out solving challenges effecting the special needs child.

Listening and Talking

It is in the spirit of connection that we bring forth all of the knowledge and skills from Part 1, Our Practices, on ways to enhance communication and exchange ideas and information. Both of these sections fit together to include active listening, creating a cooperative atmosphere and initiating interest and curiosity among each other, and are most required when several persons get together to talk with each other. We also reflect back on previous parts 1 and 11 for the process and content needed for cross cultural communication using the various ethnographic, motivational, solution oriented, narrative and change based practices.

Social Outcomes from Sense of Belonging

It is also within the fold of safe connections and community linkages, where acting together to achieve referral sources begin to facilitate more adaptive functioning within the parameter of the client, family, and the peers. The client/family now begins to experience an anticipation of healing and repair. The family also may begin to experience increased coping abilities, a felt sense of internal control and strength, as well as growing sense of competence and empowerment. Here further experiences are fostered by these opportunities to come together providing for shared mastery and interdependence. Such mutually felt experiences help buffer the adverse effects of the client/family's emotional and physical world, and stimulate resilience building. These optimum

reconnecting moments may be felt in part during mentorship, friendship building, and the promotion of such positive activities and events as group recreation, service projects, and esteem building. Such engagements begin with ways to enhance mutual attachment and social bonding or the relations between caregiver and child as well as getting the family simply (not necessarily said to be easy) to talk to each other more often.

Connections Buffer Loses

It is in the benefits of our shared listening, and becoming an audience for witnessing stories to help with making things more right when there was a wrong committed, assessing opportunities for restitution stemming from victimization through injustice and inequity. It is from a sense of belonging which helps reduce the stigma and feelings of difference which promotes shame that can alienate and separate people. Normalizing feelings by being in the middle of expected roles and rituals of everyday events continues to protect, nurture and reestablish rightful ownership of preferences and action. Social and psychological core needs of trust, power, autonomy, competence, initiative, and intimacy are also attended to by the weft and warp and woven into the fabric of family stories and give origin to personal qualities which are the grist for resiliency. In community the client/family feels increasingly recognized, accepted, valued, and able to count on those closest to them.

Positive change, even if just a small step is seen in a variety of ways, and may even be manifest by the mere containment or minimization of the previously severe and complex family situations. With multi stories of client/family reunion may also come the process of resolving or ameliorating conflicts and frustration over the parent's previous perceptions of loss and broken dreams Intangible or symbolic losses or threats of separation, stress-laden pain, grief and disenfranchised mourning are eased through a collective grieving and healing. The social group may mitigate the hurt and succor the wounds helping the client/family through mourning the loss of the idealized child and other losses..

Goodness of Fit is Relational

The stories told and retold may describe a more congruent match or "goodness of fit" with parents in expectation of a child's capacity as well as the match between the community and the family. We all recognize that growth and healing are in fact taking place. Social stories develop an appreciation of the strength and abilities of the child and family and school. This task requires unqualified acceptance, albeit in an intermittent way—establishing heightened affirmations of the child, mirrored sources for being heard, seen and felt and with the family providing more optimal attachment through multiple supportive relationships around them. We all strive to convey and instill hope and positive expectations from refurbished meanings imbued by the social network. After all, it is the hope and faith in the renewed dream that is most likely to foster greater courage and continued healing creating a heightened potential for all of our personal growth, change, and inspiration for greater determination in the future.

Action Steps Toward Connections

A. Gathering the Family Together: (Click [here](#) for the Family Global Health and Well-being Scale in Appendix A}—*a family relationship rating scale.*

Families are where basic relationships generally start. However, acknowledging that serious problems often develop in families, discussion follows on utilizing community people and resources that can model successful meetings formats that families can later use in resolving problems within their own domains. From the opportunities to share meetings together in groups—we look forward to generalizing these meetings together back in the natural settings of the family network. (Click [here](#) for A Model for Family Meetings-Handout in Appendix E).

B. Attachment Relations: . One of the outcomes from reviewing the supportive features of the social support network might be the recovering of the child’s relationship with an adult caregiver so that once again special time between them might be experienced again (Click on: **Individualizing Special Parent-Child Time together- in Handouts-Appendix C.**) This may also be the basis for a mentor or big brother/sister or buddy connection.

C. Building a Dyad to Help Problem Solve: (Two heads are better and stronger than one) Begin to search just one or two family members or good friends as you further look to the community and school. Our hope is that exploring the problem you have with your child to come up with solutions will be better managed if the parent doesn’t have to be alone with this task. Solutions will likely come from talk seeking initially just one other person. Some spouses like to work together. The more couples can communicate, the stronger their collective efforts. There may be a grandparent or a church friend. Start with a phone call to discuss together the needs and ideas toward goals. Ask if this person might go to a school meeting with you sometime. Parents “helping parents” may be available through support groups as the proposed Utah Family to Family Networks of DSPD and the Utah Parent Center. List Serves and chat groups are also accessible. See Advocacy and Support under Favorite Web Sites— **Other Resources Menu**

D. Gathering more Helping Persons: A common and recurrent theme from previous parts is gathering all of the appropriate people who are involved in the problem or its solution. These may include family members, extended family, friends, teachers, administrators, a health provider, a psychologist, a social worker and others as needed. (Click [here](#) for Family Support Chart, Appendix B) An alternative to this method might be constructing a Family or Eco-genogram (Click [here](#) for Genogram in Appendix Part 11) in order to show the multiple relations and how resources configure into these family-community relationships.

E. Outcome Focus/Addressing Given Concerns. What are the problems? What are the goals? What are the solutions? Is there a step-by-step plan? A statement of problem can be rewritten in a positive way and become a goal. (Click [here](#) for look at Treatment Plan in this section, Appendix J)

F. Assignments, Follow-up, Maintenance and Transition. Unless accountability is included, goals are not always obtained. Think about a purpose for the meeting. Sometimes problems want solving by means of understanding root causes and often this is not the most productive way to set goals. The solution-focused approach is an inductive method that bypasses problem analysis. Most Western approaches are deductive, logical and problem solving. If that doesn't work, other solutions may encourage more progress. **(Click [here](#) for Solution Focus handout, Part 11, Appendix or (Click [here](#) for Steps to follow in Collaborative Coordination in Appendix D)**

G. Written Record. Notes should include people present, background situation, observations, health situation, strengths, concerns, plans that note who is responsible for carrying out plans, and finally, a follow-up date for a meeting or telephone conference. **(Click [here](#) for School and Community Conference Form, Appendix F)**

H. Networking. “When the heart stops beating, the blood no longer carries oxygen, nutrients and wastes to various body parts and death occurs; even so, when there is little or no communication between persons, the relationships die.” Care Coordination is a term parents and medical folks talk about when there are chronic health problems with complex needs involving multiple providers to keep the big picture in focus by sharing assessments, communicating needs and progress, and case management of limited resources. We value this opportunity to look at many levels of the child-family ecology especially as a source for hidden resources and solutions. An overview of Care Coordination and the Tool Kit is available on the Home Page About the Medical Home at www.medhomeportal.org/

1. Telephone Conferences. Here, a group of health professionals, such as a physician, a psychologist, a social worker and a nurse gather around a speakerphone and discuss problems and solutions with a teacher or group of school personnel who are also sitting around a speakerphone or other conferencing tool. Telephone conferences are useful when an essential person is not otherwise able to attend. By this means of talking, shorter response times are possible and greater flexibility is afforded. We find this as a way to connect through auditory attunement and may require knowing the parties from previous face to face meetings. We try to make these sessions as efficient and focus the participants toward goal definition and accountability. We look forward to when video teleconferencing and video streaming will be more available.

2. School and Small Group Consultation and Conferencing. These are meetings to improve an at-risk child's school experience as well as ways to partner and participate together. It is a joint effort to develop strategies, which includes a teacher, a resource teacher, a counselor, the principal, possibly a health representative (if not in person, then with information that may have been obtained earlier by phone), perhaps a school district representative, the parents, a parent advocate, and the child, who may elect to bring a friend or a pet. Again, completing a **School Conference Arrangements Form**, Appendix F [**Click [here](#)**] would include names of those attending, problem background, observations, medical concerns, strengths, plans and who will

carry them out, identification of a core team and a follow-up meeting date. Sometimes the health provider will need to submit their input in alternative ways elicited under Facilitative Needs under Conferencing below. The Medical Home web under Schools and Education offers a *Med Home School Evaluation Recommendations* form which offers ample opportunity for such communication so the team may have a release to information, best way to contact and who, a description of the medical conditions and their impact on function with other ideas and concerns. It would be important to achieve two way talk with the provider when the diagnoses are multiple and complex.

Guide to Conferencing

Conferencing is an instrumental process available to most any school or other service. Locally, it is being utilized along the Wasatch Front and other parts of the state in cooperation with the ABLE Team of the State Department of Health. Conferencing can be a means of acquiring additional information in a multi disciplinary setting. For example, using the IEP model conferencing could include other providers beyond school personnel at these meetings, as requested by the parents. If the child is an IEP recipient, the parent has authority to include others in the group. This setting offers the following options:

1. Challenges, needs and concerns are delineated.
2. Promotes respect and affirming each participant's role and is nonblaming.
3. Facilitates a coping process among those concerned.
4. Identifies the balance between the risks or positive capacities or strengths within the child in his environment at home, in school, and culture.
5. Offers much needed assistance in containing the challenges.
6. Assesses intervening resources.
7. Limits the negative consequences.
8. Delegates often overwhelming intervening responsibilities that would be difficult for any one person to accomplish.

School Conferencing recognizes the following principles and values:

1. "There is strength in numbers"
2. Use what is available
3. Brings together the several "views of the elephant" and is indispensable in securing the most accurate perception
4. "Many hands make light work", especially in view of the often overwhelming complexity
5. Shares conversation from partnership as a catalyst for change
6. Listen to and acknowledge family stories
7. Explore and expand choices and decision-making

Conferencing group looks for new outcomes in the child and family:

1. Develops and carries out an intervention by building on the identified strengths and innate resources, including natural, informal and normative supports.
2. Parent/school partnership and bond needs to be nurtured so that the child is uniquely identified by the teacher and feels a sense of belonging, power and family-school identity.
3. Ways and means to evoke self-motivations towards actions for change, as well as measuring the progress.
4. Offers a first and most informal level of hope and strength for families and school
5. Acknowledging stronger family-school voices.

Group Composition:

The criteria used in using conference team members for a high-risk student consists of informally gathering a group of key people who are individually familiar with, important to, available to, and often already involved in the life of an identified child and family. They are gathered for the purpose of achieving collaborative understanding of/and addressing critical needs. This composition is facilitative of a ready and effective front-line service.

The members are likely to come from the school but to include the nuclear and extended family at a minimum. The composition includes both parents and hopefully with them inviting important friends or relatives for support. A “problem-defined team” is identified as whoever is connected in anyway with the problem and is invited for solutions by the parents also (other agencies who might be involved in the community as health, social service, juvenile court, mental health, or other). Finally, the family may also need to request that related service personnel from the school, such as occupational therapy, physical therapy, psychology, and nursing come to the meeting.

Group Leadership:

Group leadership is formed within the meeting where work is distributed among the members. Such roles as facilitator, scribe, and timekeeper are established at the beginning of the meeting. Some of the school personnel are likely to serve as consultants.

Group Flexibility:

The group may be generated from already existing multidisciplinary groups in school or in the community such as the Child Study Team, Child Support or Guidance Teams, Service Team, or Wrap-Around Services. Since each high-risk child is unique, the procedures for preventing, promoting or dealing with his/or crisis and individual emergencies as well as unique response time frames will be determined.

Meeting Agenda:

The meetings will usually follow the general outline of School/Community Conference Form, which includes the following:

1. The list of those attending and their roles.
2. The goals of the meeting.

3. Strength surrounding the child/school cultures.
4. Concerns and challenges.
5. An intervention plan.
6. Who will assist in carrying out the various components of the plan and when.
7. Identification of an appropriate contact person.
8. The date of the follow-up meeting.

Finally, the report that is written during the meeting is then copied and handed to the team members prior to the meetings dispersal as a backup witness of collaborative commitment and as a visual reminder of the team's transactions. A formal assessment of the meetings values and effectiveness can be completed by all present using click on ABLE's School Conference Form and School Conference Feedback Form (short and long form consumer satisfaction).

Facilitative Needs:

Invited persons may need flexibility in the way they participate. An example is when important people cannot be physically present at the meeting, but have an important role to share and can include their views by:

- ◆ Sending a representative.
- ◆ Phone conferencing with the absentee person.
- ◆ Sending a note or letter to the person.
- ◆ Consulting with the person prior to the meeting.
- ◆ E-mailing to and from the person.
- ◆ Faxing important data to the person.
- ◆ Using the Med-Home School Evaluation Service Recommendation form at www.medhomeportal.org/ (Click on Schools and Education for this form)

Opportunities to expand service interventions to a child/family need to include, but are not limited solely to such things as bus passes, tutors, trainers, swimming lessons, recreation, daycare camps and after-school supervision. Such opportunities open the way to multiple benefits for the child, to include self-esteem and identity building, respite, socialization, and other desperately needed intervention means. Other benefits may be interest and talent enhancement—with potential use in portfolio development. The team needs to continue to identify ways to cooperate possibly with other agencies, as a participating vehicle for acquiring these kinds of activities. **(link to Part IV for ideas)**

Finally, Group Conferencing is not a program, but a basic process, and potentially a preliminary to core teaming involvement. Policies and procedures for core teaming are further accessed under **collaborative coordination and team building in Appendix D (click on for core team)**

School Conferencing Example

An interdisciplinary team was called. It was made up of the school child study team, which is a group already consisting of different disciplines including the principal, a special education teacher, a regular education teacher, a school psychologist, and the parents. (The parents were felt to be not quite ready to be “customers” or were ambivalent in the “contemplative stage” of change.) We joined this group as a health provider, but could have used other forms of communication with the school than the one we chose—going to the school.

Testing was reviewed along with observations. Peoples’ interpretations but primarily descriptions of Adam’s behavior were also offered. We were looking for evidence of anxiety (agreed by others), and possible obsessions and autistic-like behaviors (disagreed by most). Although achievement testing was normal, staff felt he seemed to have principle learning problems, and they offered Resource helps to help manage. Their impressions seemed to be verified too by separate language testing with below average and written language deficiencies. Primary concerns related to Adam’s escape behaviors were that he might be having anxious attachment or at least anxious protections (reliable) with frustration (also a reframe) as a source. Sometimes he would lash out, or hit, which may have been a basis for his oppositional behaviors. (Overall, we were seeking a reliable measure of his behavior as a reflection of a background from likely losses and depression in family rather than one of being a so-called “bad kid”.)

Intervention suggestions included daily tracking and monitoring behavior shaping, using behavioral momentum. We used two-way Home Notes to increase communication both to and from parents. We also used a continuous reinforcement schedule for positive behaviors—with lots of praise statements and mystery motivators for each appropriate half day, and with rewards of allowing him to show off his car collection and doing puzzles, which he loved. Extra choices were offered (both acceptable). A crisis plan was also devised to include redirection and a quiet place where he could be given permission to leave to go (initially using his avoidance to reinforce.) The psychologist took a major role to keep up with him and see him frequently, resulting in eventual bonding and mutual respect. We would keep track of the obsessions and panic times. The Autistic Spectrum rating scale and Cars were to be screened.

Follow-up was agreed upon to include a teleconference in 30 days. Since the meeting, we have prescribed through his primary care doctor, Strattera for impulse and disorganized behaviors. This was eventually stopped as school reported at follow-up meetings that it was of little help. By policy, the schools have a way to document plans for health-related inclusion for special needs children where the health provider can have an input such considering that the child’s performance would be enhanced from this information. The “Health Care Plan” might include such things as medication, special procedures, and including unusual equipment or technology that may be required during the school day.

person is not otherwise able to attend.

3. Multi-systemic Core Teams or Gathering Process. Children from low-resource families who receive services from multiple agencies suffer serious consequences when, due to resource deficits, important recommendations that have been given are not enacted. However, a core of helpers can insure that a network is in place bringing home, school, church and community together. If the core team holds ample extended family members, it has the potential to continue after agency people leave. Scheduled meetings held regularly every 30, 60 or 90 days provides a safety net, and members may act as an audience to witness the telling of significant accomplishments. Through the potential for integrating the diverse parts there is offered chances for long term systemic changes that would not otherwise occur.

This affords the opportunity to re-tell what is heard in a story that fosters reflection and reordering of the information. Core team members are drawn to stories that link or share significant life-themes and values among those present as witnesses to the stories. These are powerful and moving moments that the family can then take into their own world. Of course, there is an opportunity for doing social work, but ultimately, the experience derived from narratives that are shining and unique will be the motivation to go on as a group. An important question is, “How do we secure family ownership of the meeting so that the gatherings become memorable rather than a rehash of bureaucratic thinking?” These teaming advantages include:

- ◆ Continuance of the program beyond agency involvement
- ◆ Brainstorming, using many perspectives and voices
- ◆ Measuring and supporting change
- ◆ Solving problems less intrusively
- ◆ Rendering compassionate solutions through village spokesmen
- ◆ Family empowerment and strength through parent efforts
- ◆ Use of the Family Health Promotion Plan

(Click [here](#) for the form **How to Form a Core Team by Collaborative Coordination, Appendix D**)

***Application-** The Core-Team Rating Scale is a 1-10 satisfaction scale combining many of the above features. It attempts to determine parents’ feelings about how the group conversation is going and to learn of any necessary adjustments or changes. This feedback is helpful for making meaningful improvements at the end of each core-team encounter.*

(Click [here](#) for **The Core-Team Satisfaction Rating Scale form, Appendix G**)

(Click [here](#) for the **Nursing Checklist and Development and Life Experience forms, Part II, Appendix**). ABLE uses these forms for gathering medical, academic, social, emotional and other child/family data.

Family Health Promotion Plan-FHPP

The health plan addresses all areas of a child's functioning and serves as a comprehensive blueprint for wellbeing. The plan is based on the premise that many extreme problems stem from multidetermined causes, therefore intervention is required at multiple levels of the child-family's social ecology. The idea is to integrate together body, mind, spirit and heart with environmental transactions. Chances for positive change are favored by leveraging many components of the child's world and infrastructure in the service of his and her needs and challenges. The plan is co-developed by the family, school and child, in addressing both strengths and needs. It helps families identify health promotion areas they may not have considered. Indeed, they may already be doing some of these practices and other things which work. (Enter those unlisted items already working for the family under **other**.) This plan affords building on what already works and is in place so new things to do may arise naturally out of what is already occurring.

Many of these ideas come from everyday routines. They can be thought of as primary prevention protection factors. They can be built upon to multiply their effects and become promoting factors mediating growth and development and help problems dissolve. They may not be considered necessarily secondary treatment interventions.

Solutions may come from other than problem solving the problem, Thinking and doing things may be helpful outside the original problem explanation. The FHPP was organized from a matrix (See graphic example.) comprising various levels of prevention on the left of the page as well as treatment strategies over the top right side of the page. The graphic was organized from developmental theory which supports movement and growth from interaction of the child and her environment which we described as comprising in part, family, school and the cultural community.

As a family views the FHPP, their awareness of the four areas may bring up new solutions. The systems word "equifinality" means there are many pathways to the same end. We propose giving options and choices to such means and ends to the family. Only those solutions agreed upon are included. The family requires ownership for their own solutions and they may be more likely to act on what they choose from a list or suggested by themselves rather than what's suggested by someone else; especially if there are perceived power and privilege differences. The child is also invited to participate with the adults as well as to make choices for themselves. The plan helps everyone remember what is recommended by the provider must match what is asked for and needed by the family and child. By writing "what" will be done by "whom" and "when" and "how" helps accountability, especially if the plan is to be co-created by several parties. It also gives a contractual quality and offers an agreement among the parties.

The plan is formatted left to right and describes first those elements that are preventive and primary. On the right side, these features become more involved and usually are more costly. For example, good medical control for a treatment-resistant child with juvenile diabetes would be a desired end goal. A primary strategy under the Plan's family domain may include more time with the child, possibly including "special time" Under "**Family/Home** within the FHPP lists Parent/Child Special Time.(See Able document Enhancing Family Functioning and Special Time at www.health.utah.gov/able under part 111 Our Practices.) It's likely this may promote greater competence, esteem and self-care skills. On the right side of the page would be tertiary interventions including a medical care visit resulting in increased insulin or monitoring Hemoglobin A1c testing good control. All four of the areas on the Plan suggest a biopsychosocial approach with new ways of viewing, thinking, acting or changing context for each problem or strength.

We believe that by taking a transactional and broader contextual perspective of the world of the child with disability, in conjunction with a team or a gathering of two or more with a wrap around philosophy, we are able to find a plenitude of ideas and solutions as well as to see the problem in relation to other domains which holds a crucible for the origins of resiliency.

It is from this crucible and the admixture of multiple domains from which we have distilled a panoply of "little generative experiences" which can be applied in any help-giving space promoting several larger outcome themes. These themes include a felt sense of security and connection, and a stronger voice with which one's stories can be heard, acknowledged and validated; after which one can better make sense of and see how the pieces fit together with greater understanding by which secures more meaningful stories and further enhances self identity and its relation to the both hurtful and fruitful disability experiences. The web site above takes you to For Professionals and Part IV of Our Practices for these suggestions stemming from the Family Health and Promotion Plan..

Clinical Vignette

Dear Family,

We would like to introduce you to our Family Health Promotion Plan. The purpose of this plan is to help you and the team to recognize your family's needs, plans, goals and promote healthful change. Please note that the form is divided into four areas: The Child, the Family, the School, and the Community. We have found that a combination of one or two selections from each area is needed to really achieve a desirable outcome where "the sum is more than the parts." A change in one area often indirectly changes things for the better in other areas. With this in mind, we ask you to look over this form and add your ideas to what's written and bring it the next time we meet.

During your next visit, we'll be using this form as an outline for working together. Don't worry if you are not sure what we mean by some of the items. For now just use the form to jog your memory about what you would like to see tried by the family. Together we will fill in the What, When, How and Where in the blank space below each level.

This Family Health Plan will become a part of the report you can share with other helpers working with you. We appreciate the strengths your family has to offer and the time you are sharing in this effort. We are confident that, with your help, the plan will be meaningful for your child's personal growth.

Sincerely working together,

Your team (Click [here](#) for Family Health Promotion Plan, Appendix J)

J. Topical Resource Manual-Utilizing Community Supports. Rather than just giving out a telephone number, life-giving as it may be, consider using the Topical Guide for Families of Children with Special Health Care Needs as an empowerment tool. It not only gives information of countless local resources, but also gives ideas on types of resources to look for in any community and for numerous special-needs circumstances. The Topical Guide was the basis for starting this website as a means for motivating people to feel more in charge of their community resources while building stronger self-advocates. **Click [here](#) for the Topical Guide.** See also our web home page menu, **[OtherResources](#)** especially under **www.medhomeportal.org/** (Click on Resources then Services-Community and Professional)

Appendices

Appendix A

FAMILY GLOBAL HEALTH AND WELL-BEING

Family Name _____ Date _____ Chart # _____

This scale asks you to indicate how you feel about your family **at this point in time**. This will better enable us to help your child with his or her developmental needs.

REMEMBER, there are no right or wrong answers. Please give your honest feelings.

How do you feel in the following areas:

	Serious Problem	Poor	Adequate	Good	Excellent
1. Our physical health	1	2	3	4	5
2. Our emotional and psychological health	1	2	3	4	5
3. Handling most of our financial obligations	1	2	3	4	5
4. Having enough toys and books at home	1	2	3	4	5
5. Availability /use of child care, preschool services, after school & summer play (circle)	1	2	3	4	5
6. Church and religion	1	2	3	4	5
7. Family fun, social, and recreational activities	1	2	3	4	5
8. Community services available for our child	1	2	3	4	5
9. Help from family doctor or pediatrician (if you have one)	1	2	3	4	5
10. Availability of basic material needs of living (food, housing, income, utilities)	1	2	3	4	5
11. Our ability to deal with day-to-day demands and hassles	1	2	3	4	5
12. Ability to deal with our child's delay or behavior	1	2	3	4	5
13. Discussing problems and reaching solutions	1	2	3	4	5
14. Being able to stay in control	1	2	3	4	5
15. Making sense in a meaningful way out of what happens to us	1	2	3	4	5
16. Accepting and understanding our child's condition	1	2	3	4	5
17. Handling family arguments, power struggles, and disagreements	1	2	3	4	5

(Scale continued)

	Serious Problem	Poor	Adequate	Good	Excellent
18. Discussing and sharing problems together	1	2	3	4	5
19. Our ability to handle & cope with stressful situations	1	2	3	4	5
20. Support of relatives and kin	1	2	3	4	5
21. Supporting each other during difficult times	1	2	3	4	5
22. Quality & availability of friends and neighbors	1	2	3	4	5
23. Support of spouse/partner	1	2	3	4	5
24. Time spent playing and reading to our children	1	2	3	4	5
25. Spending time together	1	2	3	4	5
26. Getting along with each other	1	2	3	4	5
27. Satisfaction with marriage	1	2	3	4	5
28. Overall family mood and atmosphere	1	2	3	4	5
29. Division of family jobs, chores, or responsibilities	1	2	3	4	5
30. Expressing affection and feelings	1	2	3	4	5
31. Sharing of discipline	1	2	3	4	5
32. Controlling our anger-without putting others down	1	2	3	4	5
33. Respect for rules and authority	1	2	3	4	5
34. Family's sense of worth and esteem	1	2	3	4	5
35. Siblings' behavior and needs fulfillment	1	2	3	4	5
36. Support from other parents of special needs children	1	2	3	4	5
37. Availability to meet with teacher/school personnel	1	2	3	4	5
38. School placement satisfaction (services meeting child's needs)	1	2	3	4	5
39. Special needs child's attendance at school	1	2	3	4	5
40. Setting aside time for myself	1	2	3	4	5

Appendix C

Enhancing Family Functioning

Individual Attention for Each Child

As important as it is to have family meetings and spend time as a family, families also benefit when parents give each child individualized attention. The following guidelines outline how giving each child attention can benefit the whole family as well as how the time can be structured to maximize potential rewards.

SPECIAL TIME

Making time for children is one of the most important things a parent can do. Children want to spend time with their parents, yet parents often find it difficult to find time for their children. Even when parents interact with their children, the parents often determine the time, the amount of time, and the activity, which detracts from the value of the interaction. Special time is one way to fill the deep, constant needs of parents and children for attention and encouragement.

Special time is for one child and one parent. The child chooses the parent, and the other parent and children make other arrangements. Parents with two or more children may have to alternate them so each has time alone with that parent.

Special time is a pre-arranged, guaranteed, and uninterrupted time that the parent spends with a child, a period of time in which the two interact without the parent being judgmental or directive. The family decides how often to have special time: daily is ideal. It is a time of day in which the parent is unconditionally available to the child. It is a commitment to the child and demonstrates by action that the child is valued and loved.

Special time is suitable for preschoolers, school age children, and adolescents.

Purposes of special time

- It offers children the opportunity to have some input and control over special time, which makes them feel competent and respected. It defuses a power struggle between parents and children by giving them decision making power and the accompanying self-respect. During special time, the parent might say, “You’re in charge. You pick the activity and I will join you.”
- By participating, the parent acknowledges the child’s rights, capabilities and needs.
- Special time can eliminate conflicts. If a child is pestering the parent to play a game, the parent can respond that he is doing something else, but “We can play the game during special time.”
- Special time allows parents to observe children up close and focus exclusively on them. The parent learns much about the child and has many opportunities to praise, encourage, and express affection.
- Special time helps parents alleviate their guilt over not spending enough time with their children.

Special time provides a form of “time in” for parents and children, an opportunity to spend time with each other, which builds a sense of trust and commitment. It provides predictable, regular, and protected time for the child and parent.

Implementing Special Time

- The parent should suggest the notion of special time at a pleasant or neutral time and simply ask the child if he/she would be interested in spending time together on a regular basis.

- The parent and child select a mutually convenient time of day. This can vary from weekday to weekend.
- The child chooses the activity so long as the activity is within the limits of parental time and financial resources, and does not violate the dignity or the authority of the parent. Parents may offer younger children a choice of activities. Suggested activities include reading a story, playing a board game, telling bedtime stories, playing a sport, fixing a broken toy or bike, and going out for a meal. Sharing a musical or artistic activity, going to a museum or library, and cooking a meal are other types of special time. Older children and adolescents may prefer to go shopping, practice driving the car, or carry out an activity over several sessions, e.g., a time-consuming board game or chess game.
- One of the best opportunities to talk is when parent and child take car rides, when they are away from the distractions and interruptions of the home.
- Generally interactive activities are preferable, but occasionally a passive activity (TV viewing) is okay and sometimes even preferable.
- The parent and child should both decide how much time to spend together, but this should be based on the parent's ability to keep the commitment. It is better to start with short periods of time to avoid fatigue and boredom, e.g., 15 to 30 minutes, depending on the child's age. Once a schedule has been established, the parent can post it on the refrigerator or in several places (in the bedrooms, bathrooms). When starting special time, it is easy to forget or cancel it.
- Parents should work hard to keep their promise of special time.
- If special time needs to be rescheduled, the parent and child need to do it together in a democratic manner.

Guidelines for Special Time

- Special time should be called by any name the child chooses, e.g., "Fun time."
- Special time is given to each child as scheduled regardless of behavior or mood. It is given unconditionally.
- If a child is disruptive or uncooperative during special time, the parent has the option to cancel it or suspend it temporarily until the child settles down. The parent might want to put the child in Time Out for a brief period or impose another consequence. The parent decides if the disciplinary action is part of the allotted time or is separate.
- Special time is not "saved up" and used to extend the time of the next special time. Each special time is for a pre-determined amount of time, but sometimes the parent and child may both agree to extend a particular session to finish an activity.
- Special time should be without interruption of any kind, except true emergencies.

Coleman, W.L. (2001). *Family-Focused Behavioral Pediatrics*. Lippencott Williams & Wilkins, NY.

Appendix D

Collaborative Coordination for Team Building

(Sharing the ABLE Team Model)

“The whole is greater than the sum of its parts.”

What is Collaborative Coordination?

Collaborative coordination is forming and using an individualized and interactive group as in a core team composed of family members, professionals and others concerned and working together in partnership for the improved outcome of an identified child and family. The model is used by the Able Program and we present it as a novel clinical-preventative practice for other programs to initiate and use also. We continue to utilize it in our collaborative team experiences, and the criteria are stated below.

The Most Complex Need Collaboration:

The child’s complex problems are found not being sufficiently resolved when it is determined that at least two risk factors in each of the four domains listed below, or a total of 12 out of the 19 factors or clinical judgment of the team and available slots based on thoughts. Although these are our criteria for the most needy, other programs will have their own combined classification determined by their own community needs. The team is referred back to “using the web” for reviewing other options at early levels of problem definition at child, family, school and community-cultural situations.

- **Child**

The Child Behavior Checklist, or Youth Outcome Questionnaire, and self-rating scales may show subscales of more than 2 *standard deviations from the mean*.

Child Neuro-developmental or select chronic medical conditions may exist.

There is often a *lack of support relationships for the child*.

The child has been subject to *abuse or neglect*.

The child is in foster care.

- **Family**

A Parent Stress Inventory with clinical significant levels.

There may be *lack of support network* among extended family, friendships and community.

There is *substance abuse*.

There are significant and chronic social-emotional and/or physical factors.

- **School**

The Teacher Report Form, or other appropriate tools, as the BASC to assess internal and externalized behavioral problems that are interpreted to be 2 standard deviations from the mean.

There is *a lack of expected academic progress* as measured by report card or other performance data, despite usual interventions or Special Education Services being provided.

The child has poor school attendance as measured by the Truancy Law.

Significant episodes of in-school or out-of-school suspensions.

- ◆ **Community-Culture**

Two or more agencies are already involved.

There is acculturation *stress* as the family is struggling to establish a new bi-cultural identity

Family is at or above 200% of Federal Poverty level.

The family is not utilizing normal community support such as extended family or friend.

The family may have no primary health care or Medical Home.
Two or more Juvenile Court involvements

Benefits of Collaborative Coordination

The parents are likely to feel ‘stuck’ because of the identified child’s poor progress. Using formal and informal assessment tools, a lack of protective factors is often identified along with high risks. Team building and CC includes the premise of brokering and enhancing the ratio of protection and risk factors.

- ◆ CC brings the parents to the group with equality and recognition of their unique expertise with the child.
- ◆ CC is commensurate with the IEP model in education to view the parent as a team member.
- ◆ CC is in alignment with national initiatives of the Surgeon General and Healthy People 2010 for working in partnerships.
- ◆ The benefits coming to the identified child will have a positive secondary effects to other children in the family.
- ◆ CC provides an on-going learning environment and training for each of its members which in turn can also be used proactively with other families in need.
- ◆ The CC provides a learning opportunity in cultural diversity and appreciation.
- ◆ Multi perspectives from each team member are used in a synergistic effect for problem solving and intervention development.
- ◆ More comprehensive understanding comes from evaluation of multiple outcomes in multiple settings.
- ◆ CC offers cost-effectiveness in dealing with ever-expanding numbers of at-risk children.
- ◆ CC provides immunization against burnout of parents and their providers.
- ◆ Medical risks in families may be reduced, ultimately reducing society’s medical costs.
- ◆ Functioning in the spirit of the collaborative ethic, the team members will feel hope for positive change.

Who is to be on the team?

The people joined together in a core team ideally are those who are important to the child, who can play a part in identifying current needs, and who can develop solutions. The team could be just a few individuals, or several persons, but ought to include the following:

- The parent or guardians
- The child, when appropriate
- A parent support person (kin, friend, parent advocate, etc.)
- Key school personnel
- An interpreter, if needed, to translate language and culture
- Pertinent agency representative(s)
- Someone to represent any medical or health concerns

The Role of a Collaborative Leader (CL)

- Collaborative Leaders and their assistants are *informally designated team members* with available time, concern, good organizational skills, and interpersonal skill such as in redirecting possible

negative or blaming momentum. They have the approval of the parents, and model hope and empowerment for the child and family.

- With parent permission, the CL or an assistant *reviews available clinical and cultural background* information.
- The CL or an assistant *guides and facilitates the discussion* and fosters support of differing points of view.
- The CL or an assistant *negotiates the delegation and distribution of various duties* pertaining to interventions, insuring that attention has been *focused on the four domains* of the child's life previously indicated: child, family, school and community.
- The CL or an assistant insures that *intervention data are provided* for the next meeting, and may delegate reminder calls to the members assigned to work on specific interventions between meetings.
- The CL or an assistant may ask a social worker or counselor to *obtain a needed genogram or family pedigree* which could include helpful information on supportive extended family members as well as critical and likely impacting events and health conditions.
- The CL or an assistant sees that necessary *releases of information are obtained*, and emphasizes confidentiality between members invited to the meeting(s).
- The CL or an assistant *summarizes the meeting*, and is careful to review *the recommended interventions* as well as *methods for tracking or measuring them*.
- With the help of an assistant, the CL *coordinates a follow-up meeting* time and place, and sees that meetings are scheduled.

What preparations are needed for the meeting?

- Invitational phone calls are made, stating the reason for the meeting and whose attendance is needed.
- Arrangements are made for an interpreter and/or translator, if needed.
- For families with non-traditional cultural beliefs, the team members try to become informed about those beliefs.
- Critical information from a prior assessment may need to be reviewed among the team members prior to the meeting.
- Internet search for cultural knowledge, social themes, and literature search for medical conditions.
- Helpers to be mindful of their own needs, threat sensitivity as well as their biases, prejudices and value conflicts.

What if a key person won't be able to attend?

- *Written information* can be obtained prior to the meeting.
- Information can be made available for the meeting by *phone*.
- *A conference phone call* during the meeting, or even a *closed-circuit teleconference* could include some persons otherwise unable to attend.
- *An alternative representative* could be sent to the meeting.
- E-mail exchange pertinent to the meeting could take place after team relationships are developed and contingent on parent permission.

What is the structure of the team meetings?

- Members are asked to introduce themselves and their relationship to the child and family.

- Someone is delegated to record legibly the meeting's attendance and proceedings.
- The child and family's strengths are discussed, as are special moments when the child may have recently shown improved behavior.
- Parents and others are then asked to share their stories, concerns and solutions.
- Collected data and current evaluations are reviewed.
- The Collaborative Leader (CL) or assistant models *acceptance, respect* and *trust* as concerns are discussed.
- *Focus* is placed on target or concerning behaviors as well as what's right and already working rather than on expressing negative feelings.
- Further focus is placed on the *setting and context* where the target or concerning and resilient behaviors occur, and the *consequences* that are given.
- The parents and others are asked for other ideas they may have, or changes they'd like to see take place.
- Brainstorming occurs, and treatment strategies are matched with identified child and parent strengths and hopes.
- Intervention plans are developed and agreed upon, along with methods of measurement.

What are the contents of the team plan?

- The child and family needs are assessed.
- Clear goals and interventions are written and developed, based on and measured by personal reporting and behavioral data. (The degree of intervention will vary with the different levels of child, family, school and community needs.)
- There is clear specification of who will do what and when.
- The selected Collaborative Leader (CL) or assistant will summarize the meeting and its plan, work to insure its proper implementation. A confidential Community Meeting Feedback (Link) completed by team members at the close of each meeting, would provide immediate feedback and helpful suggestions.
- A copy of the plan would then be made available to each team member before leaving the meeting.
- CC will and will secure the follow-up arrangements, giving particular attention to the date, time, place, and who is to attend.

How is the follow-up meeting structured?

- Flexible meetings are scheduled according to 30, 60, or 90 days or more frequent if desired.
- Introductions are made, and the child and family are asked how things have been going since the last meeting.
- The meeting is conducted in a way that the family feels heard and understood.
- Progress on the established goals is discussed.
- Positive behavioral changes as well as secondary gains are looked for and acknowledged in the child and family.
- Actual progress toward the child and family goals is celebrated, along with acknowledgement given to those who contributed to the progress.
- If significant concerns remain, a new plan is formed using the same follow-up structure.
- If no progress is being reported, consider the following:
 - Was there confusion regarding how to carry out the interventions?

- Were team members overwhelmed by given tasks?
- Were the steps for progress too large?
- Was there a mismatch between the family's preferences and culture and the intervention goals?
- Were the child and parents included in a true partnership and alliance among members?
- Were outcome measures clearly designed to reflect positive change?
- Does the team need to look closer for any positive movement toward the goals?
- Does the plan need to be modified?
- Could the child be deteriorating because of some other physical condition or family stress not yet identified?

How long does the core team continue to meet?

- ◆ Regular scheduled meetings are held as often as felt needed by parents or others to promote a proactive approach with the identified child and family, in contrast to a reactive approach of “putting out fires.” As core teaming progresses, not all initial team members are likely to be needed for future meetings. This is determined prior to each subsequent meeting.
- ◆ In time, the meetings will provide transition planning with ultimate “graduation” from the current core team to the on-going and natural support systems, such as the extended family, school and hopefully a medical home.

Appendix E

A Model for Family Meetings

PROVIDER MEETINGS: A Model for Home Meetings

In that life is full of complexities and diversity, it is important to recognize problems arising from interactions and identify strengths for use in family meetings. The family meeting suggestions on this page, although directed towards pediatricians, can be adapted for use by any helper or caregiver working with families to:

- Learn how to negotiate and how to give and take.
- Encourage use of the pronouns *I* and *we* in communicating with each other; that is, *I feel, I think, I wonder, we are aware, we are afraid.*
- Encourage every family member to share good, positive feelings about themselves and the family.
- Give everyone in the family freedom to talk and to have their say without interruptions, ridicule, or distractions.
- Allow feelings to be expressed even if they are not positive.
- Encourage every member to voice complaints, displeasures, anger, and so on.
- Be mindful of how differences in family culture may require more listening and respectful questioning to enable the conversation process to match the family's style.

Essential Aspects of Family Interviewing

1. Develop trust and rapport with each member.
2. Involve each member in the interview.
3. Explain that the meeting is a "safe place" to talk without being blamed, criticized, or punished.
4. Understand the child, problem, and family.
5. Search for strengths and past successes to renew/modify and use for solving the problem.
6. Use the family as its own greatest resource and the best expert about the child.
7. Co-construct solutions with the family.
8. Help the family adapt, cope, communicate and cooperate.
9. Be sure the therapeutic plan fits the family instead of the family fitting the plan.

Goals of the Family Meeting

1. To form a supportive alliance with every family member, a process that develops throughout the relationship. Without this alliance, the meetings will not succeed.
2. To provide directives and advice when needed, wanted, and appropriate. This advice is complementary to the family's problem-solving strategies and respects their own frame of reference, or is specific for an individual, e.g., medication for the child, or parent counseling.
3. To serve as a healthy role model, e.g., to demonstrate how to view a problem without blaming, to acknowledge others' thoughts and feelings, to share feelings and thoughts, to demonstrate affection, and to ask for help.
4. The pediatrician initially conveys that he or she is the leader. To provide leadership, guidance, and a meeting that is "safe" for each to be honest and open without fear of blame or disapproval.
5. As they become more competent and less dependent, the pediatrician helps the family develop competence and learn to prevent or solve problems (present and future) on their own. This is the ultimate goal of the family meeting.

Coleman, W.L. (2002). Family-focused pediatrics: A primary care family systems approach to psychosocial problems, *Current Problems in Pediatric and Adolescent Health Care*, 3(8), 255-314

FAMILY MEETINGS AT HOME

Family meetings at home are a very effective way for families to promote family communication and cooperative behaviors at home. In the home family meeting, like the office family meeting, every member is encouraged to share his/her thoughts and feelings and to take an appropriate, legitimate part in family-decision making. A home meeting also allows the family to practice or repeat the behaviors, the cooperation, the communication of thoughts and feelings that they have demonstrated in the office or clinic. When, in the course of family meetings with the pediatrician, the family does cooperate and communicate, the pediatrician must point this out as a way to promote the same behaviors at home. “Do you see what you’re doing here? Congratulations! This is what you want – to “get along” better, to communicate, to enjoy your family. Would you like this to happen at home? I’d like you to do this at home.”

After encouraging the family, the pediatrician needs to explain the purposes of a home family meeting, being sure to keep the expectations within their capabilities and respect their particular values and cultural beliefs.

Purposes of Family Meetings at Home

1. To provide a protected and pleasant time for the family to discuss good news/bad news and other issues without being blamed, judged, or humiliated.
2. To provide a regular, scheduled time for the family to sit down together, communicate, and organize the week(s).
3. To inform the family about everyone’s activities, interests, desires, and concerns.
4. To bring up family problems or responsibilities which need to be discussed and solved, e.g., chores, or TV viewing.
5. To acknowledge and praise everyone’s efforts and achievements of the past week(s). Individual reprimands are done privately at another time.
6. To teach children responsibility and to develop cooperative leadership. Parents have control, but encourage input from everyone.
7. To help parents decide how much power they will share. Children know they are not in control. In the meeting, parents share this limited and defined power with the children.

After explaining the purposes, the pediatrician offers some practical guidelines for family meetings at home.

Guidelines for Conducting Family Meetings at Home

1. Select a comfortable, quiet place.

2. Select a convenient time, e.g., after dinner (with a favorite dessert) or Sunday evening (with a snack).
3. Schedule meetings weekly or bimonthly. Post the schedule on a bulletin board or the refrigerator.
4. Let the family establish time frames. How long should the meeting last? (e.g., 20-30 minutes) How long can each member speak? (e.g., 3-4 minutes)
5. Determine what issues to discuss. Chores and general discipline should not dominate meetings.
6. Let each member write down topics for future meetings. Take turns keeping a record (minutes) of each meeting (taking notes or using a tape recorder).
7. Take turns chairing the meeting as is appropriate. A parent or older child might start.
8. Assign tasks at the end of the meeting and post a checklist. Encourage and support each member to be responsible.
9. Always end meetings on a positive note even if they don't always go smoothly.
10. At the end, play a family game or activity, or view a family TV show if time permits.
11. Be flexible about changing schedules if the family wants to meet at an unscheduled time, to cancel a meeting, or to shorten or extend meetings.
12. Stop a meeting that deteriorates (arguments, lack of interest). Discuss what happened at the next meeting.
13. Excuse a member who is not cooperative, is feeling ill, or has another pressing event or obligation.

Coleman, W.L. (2001). *Family-Focused Behavioral Pediatrics*. Lippencott, Williams, & Wilkins, NY.

Appendix F

SCHOOL and COMMUNITY CONFERENCE ARRANGEMENTS

Children with Special Health Care Needs, ABLÉ Program

Box 144660, SLC UT 84114-4660 (584-8552)

DATE

Submitted: _____ Client _____ DOB _____ Age _____ Grade _____

Conf Location _____ Address _____

School Phone # _____ School District _____ Year Round _____

Conf Date _____ Weekday _____ Time _____ Car _____

Tentative Date _____ Weekday _____ Tentative Time _____

Parent willing to help set up conference

Confirmed ABLÉ Staff _____ _____ Attended

_____ Position _____ ph _____

Reason for conference _____

Conference requested by _____ phone _____

Child initially referred by _____

SCHOOL CONFERENCE STAFFING

Name _____ Date _____ School _____

Grade _____ Record Review _____

Diagnosis _____

Attendance and reason for meeting (see other side) _____

Background Information and History:

Findings and Observations:

Medical Exam of Child: _____

Strengths:

Concerns and Challenges:

Plans: *(who is to carry out what, and when?)*

Follow-up Meeting _____ Conference form completed by: Recorder _____

Appendix G

Core Team Satisfaction Survey

Regarding the Program Model

Dear Team Member,

As a team member having participated with the team process in conferencing a high-risk child, your anonymous feedback will be valuable in not only providing visibility for the team model, but also in sharing ideas on how this type of intervention might be improved upon for the benefit of a larger population.

(Please circle the number or mark the answer you feel best applies.)

1. Having the conference at the local school was helpful.

(Not at all) 1 2 3 4 5 6 7 (Very Much)

a. Having members from different disciplines added needful insight.

(Not at all) 1 2 3 4 5 6 7 (Very Much)

2. I was satisfied with the conference outcome.

(Not at all) 1 2 3 4 5 6 7 (Very Much)

a. The interactive flow seemed to be professionally competent.

(Not at all) 1 2 3 4 5 6 7 (Very Much)

b. I feel pertinent and accurate information was shared.

(Not at all) 1 2 3 4 5 6 7 (Very Much)

c. I feel the conference provided useful information.

(Not at all) 1 2 3 4 5 6 7 (Very Much)

d. Organized conference notes available for each team member was helpful.

(Not at all) 1 2 3 4 5 6 7 (Very Much)

3. Team members were supportive in their interactions.

(Not at all) 1 2 3 4 5 6 7 (Very Much)

a. I valued members who knowing and understanding of the child/family.

(Not at all) 1 2 3 4 5 6 7 (Very Much)

b. I felt the child and family were treated personally, and with positive regard.

(Not at all) 1 2 3 4 5 6 7 (Very Much)

c. There was an atmosphere of trust and acceptance.

(Not at all) 1 2 3 4 5 6 7 (Very Much)

d. Having a focus on the child's strengths was important.

(Not at all) 1 2 3 4 5 6 7 (Very Much)

4. The team shared how to better utilize other community resources such as Mental Health.

(Not at all) 1 2 3 4 5 6 7 (Very Much)

5. I feel having several members added to good results in this conference experience.

(Not at all) 1 2 3 4 5 6 7 (Very Much)

6. The following reflect some of what resulted from the team meeting. (circle letters you agree with):

- a. The meeting provided a better holistic understanding of the child.
- b. There was more clarity of direction for child/family intervention.
- c. There was more awareness of various needed resources.
- d. There was increased hope for positive interventional outcome.
- e. Parents left with less of a feeling of being alone.
- f. Family and members left with good ideas on how to cope.
- g. Other (explain).

7. I do wish the following had been different: _____

8. The following best apply in describing the conference style:

- | | | | |
|------------------|-------------|---------------|------------------|
| a. Understanding | e. Caring | i. Complete | m. Ill informed |
| b. Well-informed | f. Friendly | j. Reassuring | n. Judgmental |
| c. Meaningful | g. Helpful | k. Organized | o. Very Valuable |
| d. Respectful | h. Prompt | l. Intrusive | p. (Other): |

9. I found the following to be especially helpful or supportive: _____

10. I feel the forms used by team are reader-friendly and most helpful. (circle)
 (Not at all) 1 2 3 4 5 6 7 (Very Much)

11. What are the most valuable components of the team model? _____

12. In general, I was pleased with the conference and intervention style. (circle)
 (Not at all) 1 2 3 4 5 6 7 (Very Much)

13. Many children could be helped by this kind of program. Yes _____ No _____
 (explain): _____

14. I know of other intervention programs like the team model. Yes _____ No _____
 (If Yes, explain) _____

15. I would recommend this conference model to someone else. Yes _____ No _____

16. Using this kind of intervention model, I feel similar results could be achieved in most any school or professional setting. _____ Yes _____ No (Explain): _____

17. What kind of assistance would be helpful in encouraging more schools to use a model similar to that of ABLE in dealing with high-risk children?

18. What do you feel is the biggest barrier for other schools in starting to use a team intervention model?

Thank you for your time,

The ABLE Program

Community Meeting Feedback Short Form

Student: _____

Date _____

Meeting Location _____

Present: _____

-
1. Was the meeting respectful of cultural and ethnic factors? Yes___No___
 2. Were the child and family needs sufficiently covered? Yes___No___
 3. Was there a shift from challenges to strengths and hope? Yes___No___
 4. Did the meeting seem well planned? Yes___No___
 5. Did the meeting achieve its stated goals? Yes___No___
 6. Did follow-up plans include a next meeting date? Yes___No___
 7. Were assignments specific? Yes___No___
 8. What was most helpful in the meeting? _____
 9. What else would have been helpful? _____

Appendix H

**Children's Special Health Services Bureau
District Health Care Plan**
(Please attach forms if room is insufficient here)

School _____

Staff/Identification	
Name _____	Date of Birth _____
Parent Name _____	Emergency Telephone No. _____
Hospital Emergency Room _____	Telephone No. _____
Ambulance Service _____	Telephone No. _____
School Nurse _____	Telephone No. _____
Physician _____	Telephone No. _____
Health Care Coordinator/Facilitator at School _____	Extension _____
Direct Care Staff _____	Extension _____
Background Information Nursing Assessment	
Brief Medical History/Specific Health Care	
Psychosocial Concerns	
Child and Family Strengths	
Academic/Achievement Profile	
Goals and Actions	
Procedures and Interventions	

Child Specific Techniques

Medications

Diet

Transportation

Classroom Modifications

Equipment and Supplies

Training, Education (staff, CPR, skills checklist), (peers, students)

Safety Measures

Contingencies

Emergency Plan (If you see this...do this)

Substitute/Back up Staff (when primary staff not available)

Possible Problems to be Expected

Authorizations

Parent Signature _____ Date _____

Health Care Coordinator at School _____ Date _____

Physician: order for medication/specialized procedure (if pertinent). Initial if MD has approved. _____

School Nurse _____ Date _____

Effective Date _____ Date Health Care Checklist Completed _____

IEP if Appropriate _____ Date _____ Skills checklist for whom? _____ Date _____

April 1991

Appendix I

Health Providers Promotion/Prevention Matrix*

Intervention resources synergistically and cumulatively listed from bottom to top and left to right

		<i>Primary Prevention</i>	<i>Secondary Prevention</i>	<i>Tertiary Prevention</i>
		Protection Promotion	Screening, Impact Reduction & Early Tx	Environmental Rehab Systems
Levels of Severity	High Complexity	Voluntary Protective Supervision Safety/Crisis Plan Empathy/Service Projects Meaningful Personal Stories Identity: Memory Book & Time Line Talk Portfolio Development Cognitive-Behavior/Narrative Co-Construction Stress Reduction/Coping Skills Solution Focus Practices Home Visiting Public Postings/Recognition Enrichment Experiences Relationship-based Prevention Hope & Validation Motivational Interviewing Self Care/Bodily Care Ritual/Celebrations Parent Support Groups Parent Advocacy and Education Strengthen Goodness of Fit Inclusion/Friendship Building After School Activity Assess Strengths and Interests Risk-Protection Assessment Health Education Recreation/Leisure Cultural/Ethnic Support School Based Prevention Curricula Boys/Girls Club, Comm. Centers Worship Groups Medical Home/Dental/Nutrition Immunization/Well Child Interest/Group Activities Child Care/Pre-school/School Extended Family Support Housing/Food/Income/Insurance	Foster Care/ Adoptive Shelter Care Family Preservation Hospitalization Day Treatment Attachment/Bonding Temporary Kin Placement Substance Abuse Treatment Respite Counseling Mentoring Court Diversion Creative Funding Specialty Care Behavior Management Social Skills Training Early Intervention Medication Family Assessment Child Screening Prevention of Academic/Social Failure Student Occupational Educational Plan Early Sick Care	Residential Services Interagency Consultation Teams Multiple Agency (LIC) Integrative Services Apprenticeships Vocational Rehabilitation Vocational Education DSPD Core Teams Job Shadowing/School to Work Collaboration/Wraparound Transition Plans Cluster Units Self Contained Resource Special Education IEP/504/ Health Plan Functional Analysis/Antecedent Control Social & Contextual Supports Networking Assistive Technology
	Multiple Conditions Identified With Agency Involvement			
	Minimal Identified Risks			
Normal Population With Unidentified Risks				

*See corresponding FHPP (Family Health Promotion Plan): A parent directed worksheet on the reverse side.

Appendix J
Family Health Promotion Plan
 (Needs, Goals and Change Strategies)

Name:

Chart #:

Date:

Those in attendance: Mother:-Father-Child-School

List others:

Child

- | | | |
|----------------------------------|--------------------------------|--------------------------------|
| 1 Nutrition/Sleep behavior | 8 Social Relations | 15 Dealing with Loss and Grief |
| 2 Medical/Dental needs | 9 Play/Activities/Rewards | 16 Strengthening Coping |
| 3 Body Work/Exercise | 10 Daily Living Skills | 17 Self Identity/Development |
| 4 Self Calm/Relaxation | 11 Talent Build/Hobbies | 18 Individual/Group Therapy |
| 5 Self- Care and Self Management | 12 Self Esteem Building | 19 Medication |
| 6 Child Attachment/Empathy | 13 Pain/Illness Management | 20 Other |
| 7 Stating Wants and Feelings | 14 Anger/Aggression Management | |

Child Plan (what, by whom, when)

Family/Home

- | | | |
|---------------------------------|------------------------------------|---------------------------|
| 1 Home/Food/Job/Insurance, etc. | 8 Parent/Child Special Time | 15 Family Service Project |
| 2 Child Care/Respite | 9 Information/Education | 16 Behavior Mgt. Training |
| 3 Help w/ Brothers/Sisters | 10 Recognition/Awards | 17 Family Counseling |
| 4 Boundaries/Structure/Routine | 11 Chores/Pets/Roles | 18 Caregiver Treatment |
| 5 Stress Control | 12 Leisure/Recreation | 19 Home Support Services |
| 6 Kin/Parenting Support | 13 Celebrations/Rituals/Traditions | 20 Other |
| 7 Family Sharing Time | 14 Cultural/Spiritual | |

Family Plan (what, by whom, when)

School/Education

- | | | |
|-------------------------------|-------------------------------------|--------------------------------------|
| 1 Family-School Bonding | 9 Recognition Experiences | 17 Other Skill Building |
| 2 Attendance Strategies | 10 Assign Helpful Tasks | 18 Student Ed Occupation Plan |
| 3 School Stress Reduction | 11 Positive Home Notes | 19 Individual Health Plan/504 Plan |
| 4 Sense of Inclusion | 12 Achievements/ Projects/Portfolio | 20 IEP-Related Services |
| 5 Teacher/Child Compatibility | 13 Build on Strengths | 21 Family Education/Counsel Center |
| 6 Friendship Building | 14 Other Success Experiences | 22 Marketable Skill Development |
| 7 Buddy/Activity Groups | 15 Learn Strategies/Self Management | 23 Vocation/Education/Rehabilitation |
| 8 Mentor/Coach/Student Tutor | 16 After School Activities/Homework | 24 Transition/Closure |
| | | 25 Other |

School Plan (what, by whom, when)

Community

- | | | |
|--------------------------------|-----------------------------------|-------------------------------------|
| 1 Safety Crisis Plan | 9 Health Program/PHN | 16 Coordination of Services |
| 2 Care w/ Trust, Respect, Hope | 10 Mental Health | 17 Core/Team/Wraparound |
| 3 Network Building | 11. Services for Persons w/Disab. | 18 Family/Agency/Community Together |
| 4 Parent Support Groups | 12 Home Visitation | 19 Family Preservation |
| 5 Parent Information Center | 13 Mentor/Work Experience | 20 Other Human Services |
| 6 Parks and Recreation/Camp | 14 Volunteer Work | 21 Substance/Abuse/Gang Prevention |
| 7 Religious Affiliation | 15 Monitoring Progress | 22 Legal Advocacy/Court |
| 8 Cultural Advocacy | | 23 Other... |

Community Plan (what, by whom, when)

Additional Information:

Next Appointment:

Reports to: 2 copies to chart

Follow-up Meeting _____ Conference Form Completed Recorder _____

Dictated by _____

References and Resources III:

- Apgar, J. (2003). "Stress and Social Support" in *Handbook of Health Communication*. T. Thompson (Ed.). Lawrence Erlbaum.
- AAP. (2002). *Caring for Children with ADHD: A Resource Toolkit for Clinicians*. [Small amount of money for checklists, home note formats, forms, other guidance tools that can be used over again]
- Bracht, N. (1990). *Health promotion at the Community Level*. Sage. [Partnerships in community organization and social change—what is community?]
- Clay, D. (2004). *Helping School Children with Chronic Health Conditions*. The Guilford Press. [Special needs children getting back into school, reintegrating and making accommodations]
- Chamberlin, R. (1988). *Beyond Individual Risk Assessment: Community Wide Approaches to Promoting the Health and Development of Families and Children*. Edited by Division of Maternal Child Health Conference proceedings.
- Combrinck-Graham, L. (1990). *Giant Steps*. Basic Books. [Community ways to build competencies for children]
- Developmental Research and Programs, Inc. (1996). *Communities that Care* [Prevention strategies using what works with the child in the family, school and community]
- Hallowell, E. (1999). *Connect*. Pantheon Books. [Bringing parts into a whole]
- Ivey, A. (1993). "Network Interventions" in *Developmental Strategies for Helpers*. Micro-training Assn: Amherst, MA. [Using developmental counseling and therapy in the community]
- Jellnick, M. et al. (2002). *Bright Futures in Practice, Vol. 1 and 2*. MCH/ HRSA: National Center for Education. [Mental health with self, family, friends and community]
- Katzenbach, J., & Smith, D. (1993). *The Wisdom of Teams*. Harper Press.
- Leff, P. et al. (1992). *Building the Healing Partnership*. Brookline Books. [By coming together we can make things better for children with disabilities]
- Levi, D. (2001). *Group Dynamics for Teams*. Sage.
- Lewis, J., Lewis, M., et al. (2003). *Community Counseling* Thomson/Brooks Cole. [Empowerment strategies for prevention, outreach, being a change agent, and advocacy]
- Lynch, E. (2000). *Developing Cross-Cultural Competence*. Paul Brookes.
- Metcalf, L. (1995). *Counseling Toward Solutions*. Jossey Bass. [Great resource for turning problems into solutions in school]
- National Research Council: Institute of Medicine. (2002). *From Neurons to Neighborhoods, the Science of Early Childhood Development*. [The brain is dependent on healthy context, environment, and overall positively worked through experience]
- Olson, L. (1997). *The School to Work Revolution*. Perseus Books. [Transition from school to workforce]
- Pool, M. (2003). "Groups and Teams in Health Care: Communication and Effectiveness" in *Handbook of Health Communication*. T. Thompson (Ed.) pg. 369-402. Lawrence Erlbaum.
- Rushton, F. (1998). *Family Support in Community Pediatrics*. Praeger Press. [Medical home, home visitation, good schools, public health nurse, all create positive health outcomes by families perceived support]
- Ryan, B. et al. (1995). *The Family-School Connection* Sage. [Relates family support and school relations to kids performance and development]
- Schorr, L. (1997). *Common Purpose: Strengthening Families and Neighborhoods to Rebuild America*. Anchor Books.
- Scutchfield, D. et al. *Principles of Public Health Practice*. Delmar.
- Sue, D. et al. (1998). *Multicultural Counseling Competencies* Sage. [Individual and organizational development]
- Siegel, D., & Hartzell, M. (2003). *Parenting from the Inside Out*. Tarcher. [Suggestions for parents about how to connect using stories]
- Stevens, T., & Wolf, J. (1980). *Effective Skills in Parent/Teacher Conferencing*. NCEMMH/OSU.
- Sue, D., & Sue, D. (2003). *Counseling the Culturally Diverse, 4th ed*. John Wiley Press. [Great understanding of impact of broader ethnic, societal, and institutional forces that shape individuals' development and what to do about it]

Suchman, A. et al. (1998). *Partnerships in Healthcare*, University of Rochester Press. [Collaboration in making decisions and sharing power and control]

Watson, S., & Steege, M. (2003). *Conducting School-Based Functional Behavioral Assessments*. The Guilford Press.

Wheelan, S. (1999). *Creating Effective Teams*. Sage.

Wehman, P. (1992). *Life beyond the Classroom*. Brookes. [Transition strategies for young people with disabilities]

Wyner, N. (1991). *Current Perspectives on the Culture of Schools*. Brookline Books. [Challenges, Innovations, and post-modern ways to understand how schools pass on dominant cultural values]

Ylvisaker, M. (1998). "Introduction to Functional, Everyday Interventions" in *Collaborative Brain Injury Intervention*. Singular Pub Group, Inc. [Using positive everyday routines to create contexts for change]

The American Academy of Pediatrics has promoted a strong voice for including all children in the community as the unit of care. It is through these efforts, this program dedicates the basis of each individual seen as a basis for public health practice. The AAP gives us direction through its web www.aap.org/commpeps/ and is also a source for children with special needs, and mental health resources via Bright Futures www.brightfutures.org/ Click on www.aap.org/catch/ComPedsSlides.ppt for a brief power point presentation on this entry area.

Besides having a healthy team which communicates well together and uses empowering strategies in collaborative ways to help others, there is a intention to focus on what the family wants and prefers, and what we offer in ways that match with the family's language and cultural style. It is the latter point that is highlighted here. We many times don't speak the language or understand all of the knowledge and background. We always try to get an interpreter even if some English is spoken. This person can sometimes help us understand the cultural background better and possibly even advocate or broker in ways for the family. (using the AT&T Language Line Services for interpretation at 1-800-874-9426 may not do this) The article, "The Bilingual Interview and Interpretation" by Eric Hardt in The Medical Interview (Lipkin, 1995) is helpful in understanding also the multiple roles of the interpreter. We will search for this advocacy perhaps through the family, but more so our Center for Multicultural Health and Ethnic Health Advisory Committee as well as The Utah Health Indian Advisory Board, happen to all fall under our Department of Health. Other ethnic groups may be sought from Utah's Ethnic Offices under the Governor. We strive to make sure we search a few tried and true texts that give a thumbnail sketch of many different peoples. We also remember that what we read may not apply to every person. There is usually greater difference among groups than between groups. Culture and Nursing Care—a pocket guide by Juliene Lipson et al. is very practical as well as the book Ethnicity and Family Therapy edited by Monica McGoldrick et al. Mosby also has a pocket guide, Cultural Health Assessment. Two National web sites include the Georgetown National Center for Cultural Competence at <http://gucchd.georgetown.edu/nccc/nccc7.html> and Resources for Cross Cultural Health Care <http://www.Diversityrx.org/>

The "Medical Home" or the source of Health care for the family needs to be understood as many primary care doctors and pediatricians are aligning themselves as a support for special needs children. *The Family Centered Care for Children needing Specialized Health and Developmental Services* by Terri Shelton on behalf of the Association for the Care of Children's Health further elaborates this mission. (1994)# 301-654-6549 for updated publication on this subject. Medical Home's Portal site includes information on several medical module conditions (e.g. Down's Syndrome, ADHD, and Autism) as well as Utah sources for many services and resources by category. www.medhomeportal.org/ Check out also the American Academy of Pediatrics site for ways to broker these ideas through the health provider as well as a host of medical conditions one can select. www.medicalhomeinfo.org/

Children with Special Health Care Needs' web can be accessed by www.health.gov/cshcn as well as our home agency Community and Family Health Services www.health.gov/cfhs where you can find the many Utah Public Health Programs supporting services for kids including MCH, School Health, Injury and Suicide Prevention, Nutrition, Cultural Advocacy and others. Understanding child advocacy through www.utahchildren.net/ and www.utahissues.org/ directing how to take social action and support parents and families.

The Utah Department of Education, www.usoe.k12.ut.us/ is also a source for informing people about guidelines for Special Needs Children. Recent Guidelines for serving students with special health care needs have been published and describe the several placement categories and such policy, procedures and answers to questions about children taking medication, transportation, and special services for technology dependent students. Click on **Programs** followed by **Special Education Services** for a discussion of the **Rules and Regulations** around Individualized Education Plan (IEP) as well as **Links and Resources** for a good approach to the **Utah Behavior Initiatives** and **Parent Links and Resources** where you will find www.utahparentcenter.org and one of the leading parent and professional journals under the Council for Exceptional Children. Other information through their site map will take you to Equity and the 504 Plan and Civil Rights. We like Tess Bennett's et al *Developing Individualized Family Support Plans* (1990) although for part B kids, many ideas can be presented for other children. Partnerships are key in the community. At www.ideapartnerships.org/ find under IDEA resources for 2004-commonly asked questions as a complete source of changes in this public law.

Finally, accessing Utah and National sources for Mental Health services through searching Utah Mental Health, will bring you to many of these especially Utah Mental Health Assn., National Alliance for Mental Illness and Salt Lake Valley Mental Health services.

Knowing how to access community resources by researching them and having a system to organize them is a large part of how we negotiate helping our clients take action and partner with them finding services. We have invested in the best way to broker these community resources so that people are strengthened participating in search for these. We work from The Topical Guide for Families of Children with Special Health Care Needs (2004). Areas of Needs as the first stage are identified together followed by identifying Resource Groups giving Headings. These larger Headings can be copied and given out so choices are made around many possibilities. The Topical Guide is available through this Web site (see menu). Other sources are at our fingertips including the Human Services Directory or "Redbook"—copies through The Information and Referral Center at 801-978-3333. Their web is www.informationandreferral.org/ The State of Utah as many states now offer a resource telephone number as dialing 211 for this State. Other information about Community Services with disability links is Access Utah at www.accessut.state.ut.us/ We also use the Universal on line Application System for a variety of Human Services at www.utahclicks.org